

## **Lessons from schools with high levels of support for students with Type 1 diabetes: A qualitative study**

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Schools have an important role to play in supporting the psychosocial and physical health of students with Type 1 diabetes (T1D). Good school-based support for students with T1D is related to better diabetes management and quality of life. However, support for students with T1D appears inconsistent across schools in Western Australia. Strategic capacity-building for schools, including attention to policy and practice, is needed to support students with chronic and other health conditions. This project aimed to investigate how schools provide support for the psychosocial wellbeing and disease management of students with T1D. Ten schools, identified by a hospital-to-school transition team as being supportive of students with T1D, participated in this generic qualitative study. Semi-structured interviews were conducted with school staff, students with T1D and their parents at each school. Inductive and deductive thematic analysis identified three overarching themes to encapsulate the various ways schools provided support: (a) school characteristics; (b) interpersonal support; and (c) organisational support, and eleven sub-themes outlined this support. Based on these findings, a conceptual model of support is presented. This can be used as a foundation for a professional learning tool to enhance the capacity of schools to support the wellbeing of students with T1D.

### **Background**

The incidence of chronic diseases in children and adolescents in Australia is increasing, while survival rates continue to improve (Lindberg et al., 2016). Young people with chronic diseases are therefore a growing cohort in schools. Type 1 diabetes (T1D) is one of the most common chronic diseases in childhood. In Australia, almost 6,400 children aged 0 to 14 had T1D in 2016, with approximately 1,500 new diagnoses for this age group each year (Australian Institute of Health and Welfare, 2015).

The best practice care regimen for individuals with T1D involves intensive insulin therapy with either insulin injections or an insulin pump, and blood glucose testing throughout the day to maintain stable blood glucose levels (BGLs). Good blood glucose control reduces both the onset and progression of diabetes-related complications in adolescents with T1D (Diabetes Control and Complications Trial Research Group, 1993). Many factors in the

usual school day can influence BGLs for children and adolescents with T1D, including the type of learning, stress, peer interaction, physical activity, excitement, food and exercise (Goss et al., 2018). Additionally, BGLs can affect learning through impact on mental flexibility and decision making (Kodl & Seaquist, 2008). As children and adolescents spend a significant portion of their day at school, schools play an essential role in providing a safe, supportive and flexible environment for students with T1D to not only enhance their physical health but also their psychosocial wellbeing.

Approximately one third of children and adolescents with T1D have experienced mental health difficulties (Northam, Lin, Finch, Werther & Cameron, 2010) and significant numbers have neurocognitive impairment (Northam et al., 2009). Psychological distress and anxiety are also significant problems in this population (Delamater, de Wit, McDarby, Malik & Acerini, 2014). In addition, childhood onset of T1D negatively affects school achievement (Persson, Dalhquist, Gerdtham & Carlsson, 2013). Studies have found that good school-based diabetes care and psychosocial support for students is related to better diabetes management and quality of life (Wagner, Heapy, James & Abbott, 2006). In addition, schools that promote social connection for students with T1D can help counteract feelings of stigma and isolation (Schabert, Browne, Mosely & Speight, 2013). However, children with diabetes often feel that “dealing with diabetes in school is among the worst experiences they have faced while growing up” (Schwartz, Denham, Heh, Wagner & Shubrook, 2010, p.48).

Recent research with parents of children with T1D showed that 43% felt the support for their child’s chronic condition at school in Western Australia was inadequate (Fried et al., 2018). The level of support that a child or youth receives can depend on where they live, the school they attend, and often their family’s advocacy efforts (Reavley, Bassilios, Ryan, Schlichthorst & Nicholas, 2015). Consistent support across schools is needed so that parents can have confidence in sending their child with T1D to their local school rather than having to seek out and travel to a ‘supportive’ school. To date, most school interventions to support students with a chronic disease have focused on improving staff knowledge of the disease (Shui, 2001). However, novel, complex school interventions are needed to achieve consistent support for students with T1D (Edwards, Noyes, Lowes, Spencer & Gregory, 2014).

As schools often face challenges when implementing support strategies for specific groups of students, strategic capacity building is needed (Domitrovich et al., 2008). Capacity building involves enhancing the school’s ability to implement change beyond the development of individual capacities (Whitman, 2005). Interventions or tools that enable schools to identify areas of need and continuously improve practice can build capacity (Whitman, 2005). Areas of need may be determined by identifying: (i) schools’ current experiences with T1D students; and (ii) characteristics of school environments that enable or inhibit staff implementation of best practice in physical and psychosocial care (Reavley et al., 2015). While studies in Australia and world-wide have investigated school experiences from student perspectives, little is known about how schools support students with T1D successfully.

The research questions for this project therefore are:

1. How do schools in Western Australia, reported as engaging in best practice strategies for supporting the psychosocial wellbeing and disease management of T1D students, consistently provide this support?
2. How do the findings of this research inform the foundational development of a professional learning tool to improve the capacity of schools to provide multi-faceted support for students with T1D?

## **Method**

A generic qualitative design was utilised as it was considered the project did not align with the philosophical assumptions common to established qualitative methodologies (Caelli, Ray & Mill, 2003). The quality of the study was addressed through attention to, and outline of the following: what motivates the researchers to undertake the study, details of the research methods, strategies to establish rigour, and the researchers' role in data analysis (Liu, 2016). The lead researcher has a background in education. Her research has aimed to improve outcomes for students at risk of reaching their potential.

### **Sampling and recruitment**

Maximum variation sampling was used in recruiting schools to obtain broad insight of school staff perceptions together with the students with T1D and their parents in varied school contexts (Patton, 2002; Palinkas et al., 2015). Hospital to school transition staff at the School of Special Educational Needs: Medical and Mental Health (SSEN: MMH) identified schools known by them to provide high levels of support for students with T1D. Referred schools were stratified as to their type - primary, secondary, or kindergarten to year 12 schools; sector - independent, Catholic or government, and location - regional or metropolitan area.

A total of 20 schools were identified and 12 of these were approached by the SSEN: MMH to participate in the first round of the study. Two school principals did not agree to participate, one because the school was too busy and another because they no longer had a student with T1D. The size, sector and location of the ten consenting schools can be seen in Table 1. All except one of these schools had more than one student with T1D.

Principals of the ten consenting schools provided the names of 26 staff members who were significantly involved with supporting students with T1D at their schools and each provided consent. To triangulate the data from the school personnel and strengthen research rigour, parents of students ten years or older with T1D at the consenting schools were approached to provide permission for their children / themselves to participate. Of the 16 students and parents approached, six students and three parents agreed to participate. A total of 35 people participated in the study (see Table 1). The Child and Adolescent Health Service Ethics Committee at the Princess Margaret Hospital for Children in Western Australia (now Perth Children's Hospital) approved the protocol for this research.

Table 1: Participating schools

| Participating schools | Sector      | Size | Location | Interviewees  |
|-----------------------|-------------|------|----------|---|
| Primary               | Government  | 295  | Metro    | 1 deputy, 1 teacher, 2 education assistants                                       |
| Primary               | Government  | 543  | Regional | 1 deputy, 1 teacher, 1 parent, 1 student  |
| Primary               | Independent | 200  | Metro    | 1 principal, 3 teachers   |
| Primary               | Independent | 320  | Metro    | 1 school nurse, 1 education support coordinator, 1 admin                          |
| Primary               | Catholic    | 169  | Metro    | 1 deputy, 1 education assistant   |
| Secondary             | Independent | 1150 | Metro    | 1 pastoral care leader, 1 school nurse, 1 camp coordinator, 3 students, 2 parents |
| Secondary             | Catholic    | 954  | Metro    | 1 year coordinator, 1 deputy, 1 student services coordinator, 1 student           |
| Secondary             | Government  | 440  | Metro    | 1 first aid officer, 1 deputy   |
| Secondary             | Independent | 779  | Metro    | 1 outdoor education teacher, 1 year coordinator                                   |
| Secondary             | Independent | 300  | Metro    | 1 teacher, 1 student  |

### Procedure

Procedures for this project were regularly discussed with an experienced researcher who was not part of the immediate research team. Semi-structured interviews were conducted with consenting participants at the schools or the homes of the students and their families. Three of the student interviews were conducted with a parent in attendance. Interviews were digitally recorded with the participants' permission and transcribed verbatim and ranged from 15–50 minutes in duration (average 32.5 minutes). A member of the research team trained in qualitative methods conducted all interviews.

Participants were encouraged to speak freely without interruption about their experiences. Field notes taken after each interview and a semi-structured interview guide with questions and prompts provided consistency and dependability (Kvale, 2006). Specific guides were developed for teachers, principals, parents and students. School personnel were asked questions such as: What do you believe your role is in relation to students with T1D and their families? In what ways do you personally support students in your class or school that have T1D and their families? In what ways do other staff members support students with T1D? What does the school do to support students with T1D? What difficulties are there in supporting students with T1D and their families?

### Analytic approach

Data were analysed using the six-stage iterative process of thematic analysis described by Braun and Clarke (2012). Transcription by the interviewer allowed familiarisation with the interview data and field notes. *NVivo* software was used to organise data and record notes related to coding. The data analysis was ongoing during data collection. Although additional schools were identified to participate we did not recruit further as the same themes were emerging after data analysis from the ten schools.

Analysis of the data was driven both inductively from the data itself, and deductively by pre-existent theory. During the ongoing process of data analysis, the social-ecological model (McLeroy et al., 1988) revealed itself as an appropriate explanatory framework consistent with identified themes emerging ground-up from the data. This was not rigidly applied to the data, but rather utilised in a flexible manner to allow for amendments based on themes emerging inductively through the text.

Through constant review of the data, fifty-two codes were initially identified representing ways that schools support students with T1D. These were broadly grouped into three themes closely aligned with three levels of the social-ecological framework: (a) school characteristics, (b) interpersonal support, and (c) organisational support. The codes were then further grouped to produce a total of 11 sub-themes across the levels, with notes and diagrams kept to explain the analysis process. Two researchers worked in tandem to develop and discuss themes in regular meetings (Krefting et al., 1991). To further address research rigour two participants were engaged on completion of analysis to discuss alignment of themes with their interview. The data are reported in line with the consolidated criteria for reporting qualitative research guidelines (Tong, Sainsbury & Craig, 2007).

## **Findings and discussion**

Data will be presented and discussed under the three overarching themes and will be summarised at the end of this section.

### **Theme 1: School characteristics**

The findings from this study revealed that school characteristics were integral to the support schools provided to students with T1D. Specifically, this encompassed: having knowledge, being flexible and being inclusive.

#### **Knowledgeable**

When asked about support for students with T1D, most school staff participants began by discussing the need for staff to be knowledgeable about T1D. No standardised approach to training staff was evident across the participant schools; some schools trained a small number of staff while others trained all staff. In some schools, the school nurse or parents delivered the training, although generally it was provided by external agencies. While some participants expressed satisfaction with the available training and the way it was implemented in the school, others commented that training needed to be funded externally, more accessible and prioritised by administrative staff. There were varied responses as to what school staff needed to know to support students with T1D. One student said staff needed to know only what to do in an emergency, while a parent stated “the more everyone knows, including the kids, the better”. A student commented:

The teachers need to know almost as much as I know – not like everything, but more than the students need to know. The teachers need to know what is actually wrong (Student Primary School).

Teacher knowledge of T1D has long been reported as a critical issue for the care and safety of students with T1D (e.g. Tolbert, 2009). While teacher knowledge of T1D has been found to be limited in other countries (e.g. Kise, Hopkins & Burke, 2017), little is known about the level of teacher knowledge of T1D in schools in Australia. Currently, school staff T1D training is being standardised in Australia through an Australian Government funded program guided by the three levels of training recommended by the American Diabetes Association (2014). A professional learning tool developed from this study can link to the three training levels once the Australian program is developed.

### **Flexible**

Participants discussed the need for the school to be flexible to enable students with T1D to carry out management tasks and address their psychosocial needs without being restrained by school rules and structures. One student in the study said that school flexibility needed to be negotiated with the student.

While some schools allowed the student with T1D to carry out management tasks wherever they wanted, others were more prescriptive. Treatment frequently performed away from the classroom can impact class attendance, metabolic control, and emergencies (Marks, Wilson & Crisp, 2013). However, not all students in this study wanted to conduct management duties in the classroom.

Support is needed that is really understanding of the individual student. Not over the top and not too casual... the best way to work it out is to talk to the student (Student Secondary School).

The importance of school flexibility was also identified as assisting students with T1D to develop autonomy, as explained by the following participant.

Flexibility is the key. I have found that kids with T1D love routine but within that they need flexibility and time to make decisions about their own health like: “Am I eating enough?” “Am I doing enough exercise?”, “If I want to do that athletics carnival then I am going to have to bring my carbs with me” – giving them that flexibility is important (Deputy Principal Primary School).

The goal of school flexibility is to allow all aspects of T1D management to occur with minimal disruption to the student’s normal class routines and activities (Goss et al., 2018). Student experiences managing T1D at school show that they don’t always feel free to perform management tasks and can miss opportunities to interact with their peers (Schwartz, Denham, Heh, Wagner & Shubrook, 2010). Flexible teachers have been deemed the most supportive by students with T1D (Hayes-Bohn, Neumark-Sztainer, Mellin & Patterson, 2004; Lehmkuhl & Nabors, 2008). A professional learning tool could guide school personnel in reflecting, in conversation with students with T1D, on the many

ways the school can flexibly support their psychosocial wellbeing and disease management.

### **Inclusive**

Participants in schools frequently spoke about how the culture of the school played an important role in supporting students with T1D. A school culture of inclusivity supported by compassion and a “you can do it” attitude was discussed.

So it is education and acceptance of everyone. That’s what we have our policy on - inclusion and acceptance. Everything is normalised (Education Support Coordinator Primary School).

My perception is, well, they [school staff] just care, they do what they have to do, and it’s not that hard. I’m sure it’s a lot harder than how they make it out to me but they don’t give me that worry or concern (Parent Primary School).

And just that culture that we can do it by working with the parents rather than putting it in the too hard basket (Teacher Primary School).

School inclusion of students with chronic disease needs to be guided by the principle of “only as special as necessary” to foster individual dignity, personal independence and disease self-management appropriate to a student’s age and stage of development (Lawrence et al., 2015). Inclusion needs an inclusive culture to succeed (Zollers, Ramanathan & Yu, 1999). School reflection on values and beliefs is required to create an inclusive culture (Carrington & Robinson, 2006). This reflection can be aided by a cultural audit of the school (Carrington & Robinson, 2006; Sailes, 2008) and regular monitoring (Edwards, Noyes, Lowes, Spencer & Gregory, 2014). Examples of cultural audits could be provided in a professional learning tool.

To enable an inclusive culture, participants spoke about the need to share responsibility across staff and parents. The importance of shared responsibility has been outlined in the *ISPAD Position Statement* (Goss et al., 2018).

People need to know that they are not solely responsible and that the responsibility is shared across the school (Deputy Principal Primary School).

A professional learning tool could provide examples of how shared responsibility can be promoted in schools.

## **Theme 2: Interpersonal support**

A central theme identified in the interviews was the pivotal role of schools in providing interpersonal support for students with T1D. This included disease management and academic support, emotional support, independence and autonomy, and peer support.

## **Disease management and academic support**

The level of staff monitoring was dependent on the age of the child, the stability of the student's BGLs and the type of activity the student was engaging in. For example, close monitoring was required for students on camp or away from their usual routine. A participant talked about how intense it was to take primary school students with T1D on camp but how important it was socially and emotionally for the child.

You know the camp was exhausting for all the adults involved but the fact that the kids with diabetes were included made a huge difference to them. It was like a turning point. (Education Assistant Primary School).

Students talked about teachers catching them up on work when absent and providing extra time in exam situations. One participant mentioned that she would also like extra time in tests but didn't currently receive this. Accommodations for exams, tests and quizzes are recommended for students with T1D (Lawrence et al., 2015) and in Western Australia are provided for exams when students are in year 12. Children with early onset diabetes have a disadvantage in academic achievement which can last throughout compulsory education (Dalquist et al., 2007). Learning and school achievement can also be compromised by school absence and the psychosocial burden of the chronic disease. A professional learning model could provide evidence as to the potential academic effects of early onset T1D and school strategies for connecting with T1D students who have frequent absences.

## **Emotional support**

School staff spoke of the importance of providing emotional support to students with T1D. A deputy principal commented:

... I go out of my way to get to know them, especially those kids who've got some behavioural or learning or medical issues. And I suppose that's just, silly as it sounds, sort of wandering with intent, keeping an eye on the kids as they come through Student Services to test their blood levels... keeping an eye on what's going on and trying to be one step ahead ... to work out if kids are coping with their condition satisfactorily, or not (Deputy Principal Secondary School).

While staff sometimes felt challenged by the emotional experiences of the students with T1D, they showed a high level of empathy and understanding of their mental wellbeing and the need to provide appropriate support.

As X has only relatively recently been diagnosed, in the last two years, he gets anxious and stressed and isn't always thinking rationally when he is low, so he needs a little bit of guidance because he won't always follow his action plan... It's making sure that the teachers know that when he is like that and that they will have to assist him because he gets his wires crossed (Pastoral Care Leader Secondary School).

Staff also spoke of the need to normalise the way the students feel in relation to T1D.



There were one or two occasions when she was very sad about it (T1D) and very angry. I had to manage that one day – she was very young and she got very upset, angry, frustrated. I just normalised it. I fed back to her: it looks like you are feeling very sad and very angry and it's ok to feel that. You are dealing with something that's very challenging and I can see you handling the challenges like a champion but there are times when you are going to feel like this (Teacher Primary School).

Participants in our study, as well as other research, acknowledge that emotional support is important for the management of the psychological strain associated with a chronic disease such as T1D (Hunter, 2016) and that promoting normalisation in multiple settings is a critical dimension of the quality of life for youth with chronic disease (Seligman & Darling, 2017).

Participants also acknowledged the emotional impact on teachers supporting students with T1D.

[Staff members] are scared of diabetes because [a student] had left the school in an ambulance quite a few times (Deputy Principal Secondary School).

Teachers may also need emotional support and can develop fear of hypoglycaemia related to concern about its consequences (Ryninks et al., 2015). To prevent this, teachers should be educated appropriately and encouraged to discuss their concerns with the child's parents (Goss et al., 2018). A professional learning tool could acknowledge the potential additional strain on teachers of students with T1D and make recommendations to address this. It could also provide suggestions as to how students with T1D can be emotionally supported.

### **Independence and autonomy**

The need to help students with T1D to become more independent and to feel they had some autonomy was a recurring theme in participant interviews and yet is under-researched. School staff acknowledged being guided by the parents and the student in supporting their independence. Participants were aware that even young students needed to feel they had some autonomy.

So it's giving them enough privacy to be safe but so that they maintain control, 'cause nothing is worse than having a life threatening condition that you've got no control over. They have to know they're empowered 'cause they're going to live with it forever (Deputy Principal Primary School).

If the need for autonomy and independence in children and adolescents with a chronic disease is not met, resistance to treatment can manifest (Hopkins, Green, Henry, Edwards & Wong, 2014). Practices that support the autonomy of adolescents with T1D bolster self-efficacy, which is associated with better adherence (Landers, Friedrich & Miller, 2015). A professional learning model could provide ways that schools can support the autonomy of students with T1D.

## Peer support

Participants acknowledged the need for students with T1D to have peer support.

There is normally, a little group of friends that stay back and test with her and we tried to really promote that social emotional part of it and they would ask questions and she would be happy to tell them. They know so much now about type 1 diabetes (Education Support Coordinator Primary School).

As has been found in other research, school staff participants noted that it was more emotional support that was provided by peers than practical support (Brooks, Kime, Wearden, Gillibrand & Campbell, 2015). In some instances, participants reported that this support was not orchestrated but happened naturally, given the culture of the school. School staff also spoke about how they sensitively approached peer education and checked with the parent and student first. One parent mentioned that she had been involved in educating her son's peers, while a teacher talked about how she informally educated other students.

One of his mates will most of the time come with him down here so they see what goes on and if it is a friend that hasn't been hanging around X for long then I will say – do you know what to look out for? I would ask – if you guys are out playing basketball and X started to walk funny or slur his words what would you do? (First Aid Officer Secondary School).

Students with chronic diseases can need help to find ways to tighten friendship bonds, overcome prejudices, and solicit help, with peers potentially supportive partners who could strengthen the ability of children with T1D to manage the disease (de Cássia Sparapani, Jacob & Nascimento, 2015), improve resilience (Lewis et al., 2015), quality of life and metabolic control (Wagner et al., 2006; Fisher et al., 2012). Researchers have advocated the need to set up a peer support system within the classroom to support the emotional needs of students with chronic disease (Cochrane, 2015), however peer support in schools is under-researched. A professional learning model could link to examples of peer support programs and provide research that explains the importance of peers in supporting students with T1D.

## Theme 3: Organisational support

The organisational support provided by schools was perceived as fundamental to assisting students with T1D to function effectively in the school environment. Participants discussed the importance of: allocated roles, planning and recording, transitions, and communication.

### Allocated roles

School staff discussed having clear roles in the school in relation to students with T1D and an identified key person or persons. Success of maintaining emotional connection with a student with chronic disease relies heavily on the commitment of usually one key

staff member (St Ledger, 2014). Having back-up key people was also mentioned as important.

If I'm not here we have got other people trained up to do it as well so if I'm not here he will go to the front office and one of the ladies there or the deputy will do what I do pretty much (Deputy Principal Primary School).

The roles and responsibilities of parents, school staff and children with T1D have been outlined in the *ISPAD Position Statement* (Goss et al., 2018). A professional learning tool will link to these documents and direct schools to reflect on the clarity of roles within their school in relation to supporting students with T1D.

### **Planning and recording**

In addition to the individual management plan that all students with T1D have, staff talked about a physical education plan, an emergency or critical response plan, an excursion plan and a camp plan. Schools also had ways of keeping teachers constantly aware of the students with T1D, including emailing staff reminders or discussing the needs of students regularly at staff meetings. Some schools had developed policies that helped in the support of students with T1D, including health care and inclusion policies.

In the participating secondary schools, various levels of recording were undertaken, some only keeping records if the student had experienced a significant low or high blood glucose event, while others kept daily records. Management activities for primary students with T1D were extensively recorded to “cover” themselves if something went wrong and their actions were questioned, and to learn more about the student’s BGL responses throughout the day. One staff member said that learning from experience was a vital part of her training.

... It's all recorded as well – which has taught me a lot of what I know because I can look at my recordings and go “Look there is something going on here. All his recordings have been low when he has come in this week”. And because I work so closely with him I can spot things (Education Assistant Primary School).

A professional learning model could include examples of school planning and policies in relation to students with T1D.

### **Transitions**

Participants spoke about transitions and the potential impact on the student with T1D: the end of the day (handovers to caregivers), lunchtime breaks, transitioning to a new class, and moving from primary to high school. For example:

At the start of every year there is a new handover, new PD, we refine our management plan, medical alerts have to go out at the beginning of every year, parents have to sign off on the plan, staff have to show they have read it and completed their PD and so it is reintegrated (Principal Primary School).

Participants acknowledged that students with T1D need extra emotional support when transitioning to secondary school, and this was provided in a structured way by organising the student to visit the new school with staff from the primary school before the start of the new year.

No research to date has investigated the transition from primary to secondary school for students with chronic disease. Evidence from students who do not have a chronic disease strongly suggests that the impact of the primary–secondary transition can go beyond immediate post-transfer anxieties to have a much more significant, longer-term effect on well-being and learning (West, Sweeting & Young, 2010). Individually tailored transition to secondary school programs for students with T1D, as evident at one participating school, may be important to promote wellbeing and avert any possibility of elevated levels of anxiety. A professional learning tool could assist schools to reflect on the various transitions experienced by the students with T1D and the support required.

### **Communication**

In discussing support, staff and parents talked often about communication and the need to have a planned approach. Generally, there was one person at a school responsible for coordinating communication concerning the student with T1D.

It's a whole different level of communication and you need to be prepared to give time for that... the communication with the parent, family and others, time to do the training, to set up a system or plan that will work (Outdoor Education Secondary School).

Parents talked about how frightening it was when they couldn't contact the school when needing to, while staff discussed the importance of parents being good communicators.

I guess it's more if the parents are on board with it. [One parent] is very involved and very open and communicates with us very well. If there is no communication then that's where the issues start to come in (Deputy Principal Primary School).

School staff discussed the issues they had when they could not communicate with the parents or did not feel supported by them, such as when students came to school without breakfast or without a diabetes management kit. School staff at one school also discussed the need to support the parents through communication, as confirmed in recent research (Goss et al., 2018).

We shouldn't overlook the parents' need to feel supported, us taking care of the child. Once the parent feels that level of support – it's a huge step for them to leave their child at school. If the parent feels supported, then the parent is available all the time and they gain confidence and this feeds into the child who will then grow (Teacher Primary School).

In a Western Australian study Forlin (2008) found that good communication in schools was a factor that reduced barriers to student inclusion. Good communication, reported as lacking sometimes in schools (Kise, Hopkins & Burke, 2017), has been known to improve

the confidence parents of children with T1D have in the school (Amillategui et al., 2007) and has allowed the development of open environments where children and adolescents can feel safe managing T1D (Kise, Hopkins & Burke, 2017). School personnel need to understand the variation in parent communication preferences, with some requesting daily (or more frequent) phone interaction and others just copies of weekly or monthly blood glucose logs, and should work with families to develop a communication plan (Goss et al., 2018). A professional learning tool could provide a checklist for schools to assess their communication strategies and examples of school communication policies.

## **Summary**

Overall, various forms of support were provided for students with T1D at the participating schools.

The information garnered from the interviews was used to create a model based on the structure of the social-ecological model (see Figure 1). The model reflects the type and form of support provided by schools supportive of students with T1D. The characteristics of the participating schools generated from the data provide the core in the model while the concentric circles represent the interpersonal and organisational support these schools provide to students with T1D and their families. The research sub-themes sit within each of these circles. As in the social-ecological model, elements within the different circles can affect each other. This model will be used to develop a professional learning tool to guide schools in building their capacity to support students with T1D. Each of the sub-themes will be supported with resources, including research evidence and reflection questions. The professional learning tool, once developed, will need to be used in its entirety to enable schools to reflect on their current practices and identify their strengths and areas of need in relation to supporting students with T1D.

## **Strengths and limitations**

Although our sampling was confined to only ten schools that had demonstrated strong support for students with T1D, a mix of school types was recruited, drawing on populations from a range of socio-economic backgrounds and therefore maximising the representativeness of the findings. Data triangulation was a strength of the study. However, schools in regional areas and parents and students were under-represented in this study. Throughout the data gathering and analysis process, we were aware of the potential impact of the researchers' backgrounds, experiences and expectations on knowledge generation. Our expertise in health and education, our prior knowledge about schools and students with T1D (based on our previous research and literature review), and our informal interactions with people with T1D that have occurred outside of the bounds of this research project are all likely to have impacted our understanding of the data. However, to offset this, we undertook member checking and presented preliminary data to diabetes educators and school personnel to generate discussion and provide an interpretation of the data that most closely represents the reality of the study participants.

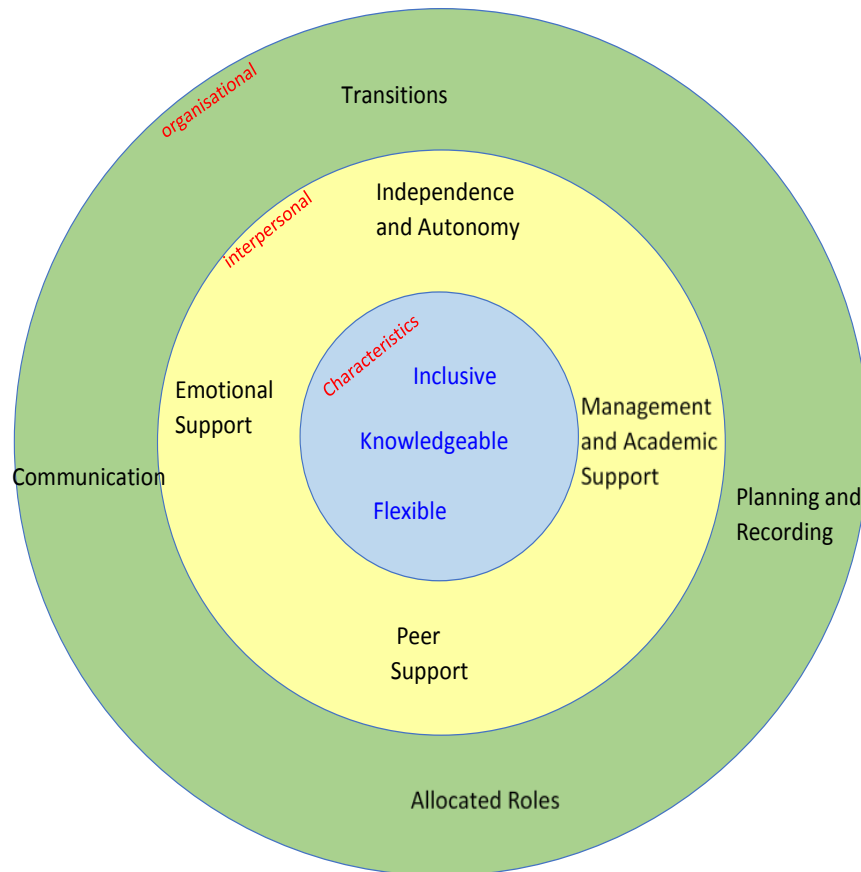


Figure 1: A conceptual model of psychosocial and physical support for school students with T1D

## Conclusion

Information gained from this study has provided evidence of the many ways schools can support students with T1D. However, there are aspects of the identified support that require further research. For example, little is known about autonomy supportive practices in schools for students with chronic disease, or successful strategies for assisting these students to transition from primary to secondary school. In addition, peer support programs in schools are under-researched.

Helping schools to meet the varied needs of their students is vital. Foundations for a professional learning tool developed from this study can provide an important starting point as a resource to build the capacity of schools to meet the psychosocial and physical needs of students with T1D. However, this will need testing in more comprehensive research, as well as adaption to support students with other chronic diseases.

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